

**Statement of Carol O'Shaughnessy**  
**Specialist in Social Legislation**  
**Congressional Research Service**

Good morning, Mr. Chairman and Members of the Committee. My name is Carol O'Shaughnessy. I am a Specialist in Social Legislation at the Congressional Research Service.

This morning I will provide an overview of long-term care for the elderly and persons with disabilities. I will briefly describe the need for long-term care services, the role of families in providing care, and the role of federal programs in financing services.

**Defining the Need for Long-Term Care Services**

Long-term care refers to a wide range of supportive and health services for persons who have lost the capacity for self-care due to illness, frailty, or a disabling condition. Need for long-term care services is measured by the need for assistance from others in performing basic daily activities, referred to as *activities of daily living* (ADLs) and *instrumental activities of daily living* (IADLs). ADLs are basic human functions, and include bathing, dressing, getting around inside the home, toileting, and eating. IADLs are tasks necessary for independent community living, such as shopping, light housework, and meal preparation.

Legislation to finance long-term care services frequently limits eligibility to persons having limitations in a specific number of ADLs, and, for the cognitively impaired, persons with a similar level of disability. This approach allows policymakers to target people with greatest need and to control costs.

Long-term care services include a continuum of health and social services, ranging from care in nursing homes to care at home through home health, personal care, homemaker services, and services in the community, such as adult day care. Long-term care may also be delivered in a variety of other settings that provide health and supportive services along with housing, such as intermediate care facilities for the mentally-retarded (ICFs/MR), assisted living and board and care facilities.

The cost of care is related to the type, intensity, and duration of services needed by clients, as well as the availability of informal assistance from family and friends. Costs may be modest to provide home-delivered meals to a frail older person living at home, for example. Cost of providing more intense home care services to a very severely impaired older person without family or community supports may be higher. Costs for 24-hour care in nursing homes or intermediate care facilities for the mentally retarded (ICFs/MR) can range from over \$40,000 to almost \$80,000 annually. Researchers and policymakers have debated whether expanded access to home and community-based care for the Nation's long-term care population is less costly than institutional care. This question is very complex and many factors must be considered, including how best to target home and community-based services, what is the most effective mix of services to divert persons from institutional care, and how to assist informal caregivers who often make a difference in keeping their family members from entering an institution.

**The Long Term Care Population** <sup>(1)</sup> About 9 million persons over age 18 receive long-term care assistance. The vast majority - over 80% - of these persons are in home- and community-based settings, *not* in nursing homes. Only about 1.6 million persons - less than 20% of all adults receiving

assistance - reside in nursing homes.

Persons age 65 and older represent about 60% of all adults who receive assistance (almost 4 million persons in community settings and about 1.4 million of the 1.6 million persons in nursing homes). But the need for long-term care affects persons of all ages. Of the 9 million persons receiving long-term care assistance, about 3.5 million are adults under the age of 65. In addition, almost 500,000 children living in the community have difficulty performing activities of daily living.

Almost one-third of the elderly, and about one quarter of adults of all ages, who receive care at home and in community services settings have **severe** impairments - that is, they need assistance with three or more activities of daily living. Without home and community support, these persons might require care in nursing homes. In addition, almost 40% of the elderly, and about half of adults of all ages, who receive assistance at home and in community settings have diminished ability to carry out tasks necessary for independent community living.

The likelihood of receiving long-term care assistance increases dramatically with age. Over half of all persons age 85 and older receive long-term care assistance, either in community settings or in nursing homes, compared to only 28% of persons age 65-84. However, regardless of age, older persons are more likely to receive long-term care at home or through community services, rather than in nursing homes.

**Demand for Long-Term Care** The need for long-term care is expected to grow substantially in the future, straining both public and private financial resources. Growth in demand will be driven by large increases in the elderly population as a result of the aging of the baby boom generation and general increases in longevity throughout the population. The first of the baby boom generation will turn 65 in just 10 years. Estimates show that the number of elderly persons alone who need long-term care assistance could grow by 35% over the next 20 years, and by 82% over the next 40 years.

While estimates vary, increases in longevity and in the number of older persons are certain to affect the demand for services. Rapid growth in the number of people over age 85 presents special challenges because the "old-old" have the greatest risk of needing care. The demand for home and community-based services is expected to grow as a result of the recent Supreme Court decision in *Olmstead v. L.C.* and advocacy efforts of younger persons with disabilities.<sup>(2)</sup> These factors will present challenges for long-term care providers, who even now face difficulties in meeting demand for services. Some research has found that about one in five disabled elderly persons living in the community report some unmet need. Persons with income below the poverty level and those with income from 150% to 200% of poverty are about equally as likely to have some unmet needs.<sup>(3)</sup>

### **The Role of Families and Informal Supports**

Most long-term care assistance is provided by unpaid family members. About 37 million caregivers provide informal care to family members of all ages. Typically, this care is provided by adult children to elderly parents and by spouses to one another.

Almost 60% of the functionally impaired elderly receiving care rely *exclusively* on informal, unpaid assistance. (Chart 3) Research has documented the enormous responsibilities that families face in caring for relatives who have significant impairments. For example, caregivers of the elderly with functional limitations provide an average of 20 hours of unpaid help each week. Some estimates have shown that unpaid work, if replaced by paid home care, would cost an estimated \$45 billion to \$94 billion annually.<sup>(4)</sup> Some estimates have placed the economic value of caregiving even higher.<sup>(5)</sup>

Many have argued that while public programs should not and cannot replace family caregiving, targeted initiatives to assist family caregivers are needed. For example, last year Congress enacted the National

Family Caregiver Support Program as part of the Older Americans Act. The intent of the program, funded at \$125 million this year, is to provide information, assistance, and respite care services to families in their caregiving efforts.

**Federal Programs** A number of federal programs directly or indirectly support a wide range of services for persons with disabilities. (Chart 4) None focus exclusively on long-term care. Eligibility requirements, services authorized, and administrative structures vary among the programs, making coordination difficult. Services provided by Medicaid and other federal programs that support long-term care vary widely by state, leading to uneven access to services across the Nation.

- *Medicaid* provides coverage for nursing home care and a wide range of home- and community-based services for persons of all ages who meet income, asset, and categorical eligibility criteria prescribed by federal and state law. Many people qualify for Medicaid benefits not by being poor, but rather, by depleting most of their assets and income to pay for care. Although nursing home care coverage is mandated by federal law, states have great discretion in deciding the extent of coverage for home and community-based care.
- *Medicare* pays for medically necessary, part-time skilled nursing and rehabilitation therapy services at home; it also pays for up to 100 days of care in a skilled nursing facility following hospitalization for individuals who need daily skilled nursing care. Medicare does **not** cover long-term care services for persons with chronic care needs or who require only assistance with ADLs.
- The *Social Services Block Grant (SSBG)* program provides a range of home and community-based services to low-income persons of all ages who meet state-defined eligibility requirements. Home care services must compete with a variety of other services for funding.
- The *Older Americans Act (OAA)* supports home and community-based services to persons aged 60 and over.
- Tax benefits for long-term care include a limited deduction for long-term care expenses and insurance premiums (provided the taxpayer itemizes deductions), tax-exempt insurance benefits, and the dependent care tax credit.

Other programs, such as state supplements to *Supplemental Security Income (SSI)*, support a range of home- and community-based services for persons with long-term care needs. Federal programs or benefits that support persons with disabilities or their caregivers include the *Family and Medical Leave Act* and the *Senior Companion Program (SCP)*, which supports volunteer assistance to frail older persons.

Despite the range of federal programs and benefits that exist, many observers believe that federal programs do not significantly support the care most people want, that is, home and community-based services. They argue that the current system is flawed because of an over-reliance on institutional care and the sometimes poor quality of such care, the heavy reliance on informal caregivers who bear most of the burden of care, and the uneven availability of home and community-based services that most people prefer over care in institutions.

### **Public and Private Spending on Long-Term Care**

The Nation spent \$133.8 billion on long-term care for persons of all ages in FY1999. This represents almost 13% of total personal health spending and an amount slightly more than the Nation's spending on prescription drugs and nondurable medical supplies combined.

Of FY1999 long-term care spending, 67% was for institutional care and one-third was for home and community-based services. Medicaid and personal out-of-pocket spending represent the two major sources of payment, 44% and 25%, respectively. Medicare plays a smaller role, representing only 14% of total long-term care spending. Private health insurance represents about 10% of the total.

**The Heavy Reliance on Medicaid** Federal Medicaid law mandates states to provide nursing facility care. In addition, states may (and all states do) provide institutional care for persons with mental retardation. States are required to provide home health services for persons who are entitled to institutional care. However, other home and community-based services, such as personal care, homemaker services, and adult day care, are provided at the option of each state.

In order for persons to become eligible for Medicaid long-term care services, they must meet strict income and assets requirements that are set by the state within federal guidelines. Medicaid pays for long-term care costs of persons whose income is low enough to receive federal cash payments under the Supplemental Security Income program (SSI) for elderly and disabled persons (\$530 per month), but can also pay part of the costs for persons whose income exceeds specified levels through its "spend down" policies (that is, a person must deplete income and resources to become eligible).

Medicaid long-term care spending in FY2000 was almost \$68 billion, more than double the amount spent in FY1990 (almost \$30 billion). (See Table 1, below.) While only a small proportion of all persons receiving long-term care services reside in nursing homes, public spending for institutional care, primarily through Medicaid, is higher than expenditures for home and community-based care. Of total spending in FY2000, 73% was for institutional care; in comparison, just 27% was for home- and community-based care. Even though spending for home and community-based services has dramatically increased since FY1990, institutional care still dominates Medicaid's long-term care spending.

The shift in Medicaid spending toward home and community-based care over the last decade has occurred primarily as a result of states' initiatives to provide a wide range of services under waiver authority granted by the Department of Health and Human Services (under Section 1915(c) of the Medicaid statute). In order to be served under these waiver programs, persons must meet institutional level of care requirements and states must assure that the cost of home and community care not exceed the cost of institutional care that would otherwise be provided to recipients. From 1990 to 1998, the rate of increase in Medicaid spending for home and community-based services has outpaced the rate of increase in spending for institutional care. Institutional care spending rose by 94%, while home and community-based care spending rose seven times over the 10 year period.

**Table 1. Medicaid Spending for Long-Term Care Services,  
FY1990- FY2000(\$ in billions)**

	<b>FY1990</b>	<b>FY2000</b>	<b>Percent change, FY1990-FY2000</b>
<b>Institutional care</b>	<b>\$25.6</b>	<b>\$49.6</b>	<b>93.8%</b>
Nursing facility care	18.0	39.6	120.0%
Intermediate care facilities for the mentally retarded (ICFs/MR)	7.6	10.0	31.6%
<b>Total home and community-based services</b>	<b>3.9</b>	<b>18.1</b>	<b>364.1%</b>
Home and community- based waiver services	1.2	12.0	900.0%
Personal care services	1.9	3.8	100.0%
Home health care services	0.8	2.3	187.5%
<b>Total long-term care expenditures</b>	<b>\$29.5</b>	<b>\$67.7</b>	<b>129.5%</b>

**Source:** CRS calculations based on Medicaid Long-Term Care Expenditures in FY2000, compiled from HCFA 64 data. The MEDSTAT Group, Inc.

Many states consider their Medicaid home and community-based waiver programs as key components in developing long-term care systems. Despite rapid spending growth nationwide, however, many

analysts consider such programs to be only a partial step in providing comprehensive long-term care services because of restrictions on eligibility and limitations in service availability throughout the Nation and within individual states. Moreover, most states spent at least half of their FY2000 Medicaid long-term care funds on institutional care; and 20 states spent 75% or more on institutional care.

## Future Directions

Changing the way long-term care is financed has drawn congressional attention for more than two decades. Previous Congresses did not reach any consensus on what policy directions to take. Broad policy approaches advanced in the past have included proposals for social insurance coverage of long-term care costs, expanded public commitment for home and community-based care, tax incentives for private financing, and combinations of these, among others. Proposals have included both incremental and large scale approaches.

Some believe that the federal government should assume the major role in expanding access to services through a new or expanded entitlement program. For example, the 1990 U.S. Bipartisan Commission on Comprehensive Health Care <sup>(6)</sup> recommended social insurance for home and community-based care and for the first three months of nursing home care. Under this proposal, the federal government would subsidize costs of care for low income persons; others would contribute toward the cost of care. Another approach advanced was a Clinton Administration proposal for capped grants to states for home and community-based care for severely disabled persons, regardless of age and income.

Others believe that costs of a new or expanded social insurance program would be prohibitive and that private sector initiatives, such as private long-term care insurance and other means of self-financing, should be promoted. Still others believe that a strategy combining both public support and private financing, such as proposals to create tax incentives for the purchase of long-term care insurance, should be pursued.

To date, Congress has chosen an incremental approach to changing the federal role in long-term care. A significant challenge for policymakers is to reconcile the concerns about the costs of these proposals, the relative roles of the public and private sectors, and ways to assist family caregivers.

Note: CRS staff Rachel Kelly and Gary Sidor made key contributions to this statement.

1. Data for this section come from an analysis of the 1994 Disability Supplement to the National Health Interview Survey (NHIS) and the National Long-Term Care Survey, *The Characteristics of Long-Term Care Users*, prepared for the Committee on Improving Quality of Long-Term Care, Institute on Medicine, by William D. Spector, et.al., 1998.

Estimates of the number of persons who need long-term care vary depending upon the number and types of ADL and IADL limitations and other factors used for measurement. Therefore, other research may show slightly different estimates.

2. In *Olmstead*, the Court held that Title II of the Americans with Disabilities Act (ADA) requires states to place individuals with mental disabilities in community settings rather than in institutions, when the state's treatment professionals have determined that community placement is appropriate, community placement is not opposed by the individual with a disability, and the placement can be reasonably accommodated. The scope of the *Olmstead* decision applies broadly to all individuals with disabilities protected by Title II the ADA.

3. Komisar, Harriet and Marlene Niefeld. *Long-Term Care Needs, Care Arrangements and Unmet Needs among Community Adults: Findings from the National Health Interview Survey on Disability*. Working Paper No. IWP-00-102. Georgetown University, Institute for Health Care Research and Policy, 2000.

4. Doty, Pamela. *Caregiving: Compassion in Action*. U.S. Department of Health and Human Services, 1998. p. 13.

This estimate is based on elderly persons who need assistance with ADL or IADL limitations.

5. Arno, Peter, et. al. The Economic Value of Informal Caregiving. *Health Affairs*, March/April 1999.

6. *A Call for Action. The Pepper Commission U.S. Bipartisan Commission on Comprehensive Health Care.* September 1990.